



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
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**Massachusetts Department of Public Health (DPH)
Universal Newborn Hearing Screening Program
Advisory Committee Meeting, 250 Washington Street, Boston, MA
Public Health Council Room, 2nd floor
Meeting Date: Monday, October 22, 2018**

Quorum was reached for this meeting – 10/22/18

Appointed members present: Jennifer Bentley, Jennifer Fleming, Aimee Knorr, Delvina Labreque, Marty Lapointe-Malchik, Christine Majeskey, Kathy Manfield, Jane Stewart, Sarah Stone

Appointed members not present: Michelle Eisan-Smith, Marly Kenna, Joan Rafferty

UNHS Staff in attendance: Martha Morris, Amarilys Triana Walsh

Others in attendance: Regan Andrade, Deb Aviles, Melissa Dowler, Elaine Gabovitch, Cheryl Glovsky, Sarah Honigfeld, Lauren McGrath, Laura Pomponi

Materials distributed:

1. Agenda
2. Draft minutes from May 14, 2018 meeting
3. UNHS Program material - Risk indicators associated with permanent congenital, delayed-onset, or progressive hearing loss in childhood
4. UNHS Program material - Audiologic diagnostic appointments: risk factor algorithm for birth hospitals
5. JCIH 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs
6. EI Program material - Early Intervention Process for Specialty Services Referral
7. Boston Children's Hospital Annual Fall Seminar
8. Beverly School for the Deaf lecture, Exploring Pragmatics
9. Massachusetts Early Intervention Consortium annual conference save the date
10. CDC Fact Sheets on CMV: Fact Sheet for Healthcare Providers, Fact Sheet for Pregnant Women and Parents, Congenital CMV and Hearing Loss

11. Flyer from National CMV Foundation
12. Proposed UNHS program material - From the Roots Up: A Family's Journey Through Services for Children who are Deaf and Hard of Hearing

Welcome and Introductions: Kathy Manfield, Chair, welcomed the group and introductions were made. Communication protocols were reviewed.

Meeting Business: Notes were distributed from the May 14, 2018 meeting. Jennifer Bentley made a motion to accept, and Jennifer Fleming seconded. The vote to accept was unanimous.

Tier One and Tier Two Risk Indicators: Martha Savaria Morris, Ph.D., Epidemiologist for UNHS presented on this topic. Martha reviewed the history of detection of infant hearing loss running from the Babbidge Report through the funding of Early Hearing Detection and Intervention programs at the state level. When screening only babies with risk factors, half of the babies with hearing loss were missed. However, universal newborn hearing screening misses the later onset cases. It is recommended that infants with risks are identified, receive timely diagnostic assessments and are tracked by the state EHDI program. MA data is limited by what is reported on the birth certificate by the hospital of birth and what is reported by diagnostic audiologists. We do not currently receive information from the birth hospital on appointments made for babies that have a Tier One risk indicator that passed the screen. We only receive appointment information on babies that did not pass the screen, as birth hospitals do not have anywhere to record the appointment information in the EBC. We do receive risk indicator information from diagnostic audiologists. The UNHS Advisory Committee developed a testing algorithm in 2012. Since that time there have been 90 cases of sensorineural hearing loss found in children that passed their hearing screen (the mean age was ≥ 2 years). Family history was the major risk factor indicated, followed next by no risk factors identified which reflects our incomplete knowledge about risk factors for late-onset hearing loss. Because of the incomplete nature of the data, no conclusions can be made, but additional hypotheses can be explored, including 1) low birth weight and prematurity without additional risk factors predict newborn hearing screening (NHS) referral but not hearing loss in either NHS refers or passes, 2) babies without known risk factors contribute greatly to late-onset sensorineural hearing loss, 3) most tier 2 risk factors are not causes of late-onset hearing loss and 4) cleft lip/palate, Down syndrome, CMV and immediate family history are strong risk factors for late-onset hearing loss.

Using this information, a discussion was held regarding possible changes to the Tier 1 and 2 risk factor algorithm. The committee agreed to add "childhood" to the Tier 1 risk factor Permanent hearing loss in immediate family and in the Tier 2 risk factor Permanent hearing loss in extended family. There was also discussion regarding the change in recommended time for diagnostic evaluation for Tier 2 risk indicators. It was decided to change the recommendation to 9 months of age from 6-9 months of age as many centers are seeing babies before they are able to get behavioral testing information. Zika will also be added per the CDC guidance.

From the Roots Up: A Family's Journey Through Services for Children who are Deaf and Hard of Hearing: Jennifer Fleming, Special Projects Coordinator for UNHS presented on this topic. Jennifer reviewed the work of the Learning Community and thanked the many individuals

that provided feedback on this document. The 'tree', as it is known, is meant to be a tool for families, early intervention providers and medical providers to create conversation about services available and ideas for families to think about for the future. The system of care is complex, and at the root of the tree are programs that can assist the family as they navigate it, including UNHS, MCDHH, EI and Family TIES. The visual of the tree is meant to start at the bottom and work up. The colors of the leaves represent groupings including Birth to Three, Health Services, Pre-school and Beyond and Community. The back of the document includes definitions and explanations. In addition to making this document available in print, it has been discussed to make it available on the web and in the future, as an app. It was noted that having this information available in multiple languages is important. It is also an opportunity to reassure families that may be new to the country that Early Intervention works for the benefit of their family.

Universal Newborn Hearing Screening Program Update: Sarah Stone, Director of UNHS presented on this topic. 1) It was announced the permission had been granted for letters to be sent under Dr. Stewart's signature to pediatricians reinforcing the idea of enrollment into early intervention by six months for babies who are identified as deaf or hard of hearing. 2) Beth Israel and Brigham & Women's participated in a pilot of an app that will be available nationally to parents whose baby did not pass the hearing screen to help them navigate the early hearing detection and intervention process. 3) An update on the CMV conference in September was given. There is momentum to pull together a working group of folks across the state. If committee members would like to be involved, please reach out to Sarah.

Adjournment: Sarah Stone motioned to adjourn the meeting. Jennifer Fleming seconded. The committee vote was unanimous.